

Inflammatory Bowel Disease: Top Resources for Children, Adolescents, and Their Families

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Inflammatory bowel disease, Crohn's, ulcerative colitis, Web, information, support

It is estimated that more than 1 million people in the United States have inflammatory bowel disease (IBD), and about 10% of them are children (Bousvaros et al., 2006). Approximately 20% to 25% of all cases of IBD are diagnosed in childhood or adolescence (Gray,

Denson, Baldassano, & Hommel, 2011). The timing of the diagnosis compounded with the developmental demands of childhood and adolescence may have a profound physical and psychosocial impact on youth affected by IBD. Effective coping with this chronic and debilitating disease will require support from professionals, family, friends, and others living with IBD. This article will focus on high-quality resources on the Web and mobile health technologies that provide youth and their families with information and support for living with the challenges and uncertainties of IBD.

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ABOUT IBD

Inflammatory bowel disease (IBD) refers collectively to a group of chronic disorders: Crohn's disease (CD), ulcerative colitis (UC), or indeterminate colitis (IC). The type of IBD generally is determined by the part of the intestinal tract that is affected. Crohn's disease causes inflammation in any part of the gastrointestinal tract from the mouth to the anus and affects all layers of the intestinal wall. The inflammation associated with UC usually begins in the rectum and extends proximally in a continuous pattern; eventually, it may affect the entire colon. When a firm diagnosis of CD or UC cannot be made on the basis of standard diagnostic tests, a child with colonic disease is described as having IC (Kane, 2010).

The specific etiology of IBD is unknown. A common hypothesis for the cause of IBD is that it is the result of an unregulated intestinal immune response to environmental and bacterial triggers, probably in a host susceptible to genetic invasion (Haas-Beckert & Heyman, 2010). This response leads to the uncontrolled inflammation that causes damage to the gastrointestinal tract, resulting in symptoms.

BOX 1. General information and support for patients with inflammatory bowel disease and their families

- American College of Gastroenterology
<http://gi.org>
- American Gastroenterological Association
<http://www.gastro.org>
- Australian Crohn's and Colitis Association
<http://www.acca.net.au>
- Centers for Disease Control and Prevention
<http://www.cdc.gov/ibd>
- Crohn's & Colitis Foundation
America: <http://www.ccfa.org>
Canada: <http://www.ccfca.ca>
- ImproveCareNow (ImproveCareNow Network)
<https://improvecarenow.org/>
- National Digestive Diseases Information Clearinghouse
<http://digestive.niddk.nih.gov>
- National Health Service
<http://www.nhs.uk>
- North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
<http://www.naspghan.org>

The symptoms associated with IBD are characterized by periods of exacerbation and remission. Predominant symptoms that occur during flare-ups or exacerbations may include diarrhea, blood in the stool, and abdominal pain. Problems outside the gastrointestinal tract also may be associated with IBD. Growth failure and subsequent pubertal delay is a common manifestation of IBD in children and is related to the inflammatory process, decreased nutritional intake, malabsorption, and extensive glucocorticoid therapy (Haas-Beckert & Heyman, 2010). Extraintestinal symptoms may appear in other parts of the body and include health problems related to the eyes, bones, joints, skin, kidneys, and liver (Kane, 2010).

Children and adolescents living with IBD face difficult physical, emotional, and social challenges. Exacerbations frequently can cause affected youth to be absent from school and separated from peer and school activities. In an effort to hide their symptoms, children and adolescents with IBD may avoid telling even their closest friends about their condition, limit their food intake, or curtail use of the restroom. This attempt to hide their symptoms may lead to feelings of anxiety and depression as a result of the realization that they are different from their peers. Children with IBD appear to have more depression and anxiety than normal peers or children with other chronic illnesses (Bousvaros et al., 2006). Alterations in physical appearance and growth failure as a result of adverse effects of medications or the disease may lead to difficulties with self-esteem. In addition, periods of increased disease activity may

adversely affect family functioning (Mackner, Sisson, & Crandall, 2004).

Initial treatment usually focuses on medical therapy aimed at controlling inflammation of the gastrointestinal tract. Most persons with IBD take daily medications that may suppress the immune system, causing increased risk for infection and malignancy (Markowitz, 2008). Nutritional therapy also can be used for primary management of the disease to induce remission or as additional therapy in conjunction with medical management to improve growth and correct nutritional deficiencies. Surgery is a consideration for patients for whom medical management has failed. Surgery is curative in persons with UC but is usually palliative for patients with CD, because the disease recurs about half the time within 2 to 5 years (Jacobstein & Baldassano, 2008).

RELIABLE INFORMATION ABOUT IBD

When they are diagnosed with IBD, children and adolescents, along with their families, will want to figure out what it is and how to deal with it. No doubt, many patients and their families will turn to the Internet. An important tip to share with patients is that Google, the most popular search engine in the world, recently has introduced numerous revisions to their search algorithms to improve the searcher's chances of finding high-quality sites. Entering the general phrase *intestinal bowel disease* (or the more specific phrases *Crohn's disease* or *ulcerative colitis*) into the Google search box produces many high-quality Web sites in the top search results.

Guiding youth and parents to health information sites with domain suffixes of “.gov” (the United States government), “.edu” (a school or university), or “.org” (an organization) is a good starting point to help them find trustworthy information about IBD. Box 1 includes a list of high-quality Web sites for children, families, and health professionals who wish to know more about IBD. Disease-specific information can be retrieved on these sites by entering one of these search terms: IBD, Crohn's, or ulcerative colitis. Remind patients to pay close attention to who sponsors a Web site to determine whether there may be a particular bias in the way information is presented. Commercial or “.com” sites also may provide reliable health information but may inundate the reader with advertisements and other distracting content. Some Web sites may have two domain suffixes associated with their name—that is, a domain owner may purchase “.com” (commercial) and “.org” (organization) suffixes for their Web site to ensure that an online searcher will find his or her site no matter which suffix is entered into the address line.

The WebMD Health Professional Network owns and operates several high-quality Web sites, including eMedicine and eMedicineHealth, which provide consumers

BOX 2. Web sites for youth growing up with inflammatory bowel disease

- Crohn's & Me (Sponsor: UCB, Inc.)
<http://www.crohnsandme.com>
- GastroKIDS (Sponsor: North American Society for Pediatric Gastroenterology, Hepatology and Nutrition)
<http://www.gastrokids.org>
- IBD U: Graduating to Independence (Sponsors: Starlight Children's Foundation and Children's Digestive Health and Nutrition Foundation)
<http://www.ibdu.org>
- Kidshealth (Sponsor: Nemours Foundation)
[kids] http://kidshealth.org/kid/health_problems/stomach/IBD.html
[teens] http://kidshealth.org/teen/diseases_conditions/digestive/ibd.html
- Pediatric IBD Foundation (Sponsor: Pediatric IBD Consortium)
[teens] <http://www.pedsibd.org/teens>
- UC and Crohn's (Sponsor: Starlight Children's Foundation)
<http://www.ucandcrohns.org>

IBD U, Inflammatory Bowel Disease University; UC, ulcerative colitis.

with up-to-date information about hundreds of diseases, including IBD, CD, and UC. The WebMD arm hosts the Crohn's and Colitis Exchange (<http://exchanges.webmd.com/crohns-and-colitis-exchange>), which provides information and support for its members who have these diseases. WebMD also hosts an Inflammatory Disease Health Center (<http://www.webmd.com/ibd-crohns-disease/default.htm>) that provides information, discussions, and videos specific to either CD or UC.

The IBD centers at the American Gastroenterological Association (AGA) and the American College of Gastroenterology (ACG) Web sites provide detailed information and support for individuals and families living with IBD. The AGA's Patient Center (<http://www.gastro.org/patient-center>) also provides patients with access to the evidence-based resource *UpToDate* to learn more about their disease and treatment options. The ACG's Patient Education and Resource Center Web site (<http://patients.gi.org>) includes basic information as well as videos, podcasts, and a section devoted to frequently asked questions.

The *About.com* Web site is presently owned and operated by IAC/InterActiveCorp and provides consumer information for more than 900 topic areas ranging from parenting to health to travel. The About Group hosts an IBD Center (<http://ibdcrohns.about.com>) that provides extensive information about IBD, symptoms/diagnosis, treatment, and coping (which includes a section focused on teens). An *About.com* Guide (or expert) who was diagnosed with ulcerative colitis at 16 years of age and presently works as a copy editor/staff writer for a major medical publishing house monitors the IBD Center.

Health care professionals also should recommend some reliable Web sites that patients and families can access to find information about medications that are pre-

scribed. Two good places to start include RxList (<http://www.rxlist.com>) and Medline Plus (<http://www.nlm.nih.gov/medlineplus/druginformation.html>).

WEB SITES FOR CHILDREN AND ADOLESCENTS WITH IBD

Evaluating the usability of a Web site is critical when recommending health-related sites to children and adolescents (D'Auria, 2011). Web sites designed for children and adolescents must deliver targeted information and support to different age groups. More important, the patient's age will influence how the information on a site is perceived and used.

Box 2 provides the names, sponsors, and uniform resource locators (URLs) for some excellent sites geared toward providing information and support to children, adolescents, and young adults with IBD. Most sites welcome the participation of family members and friends who are affected by this disease in some way. Encourage patients and families to explore these sites and determine which sites best meet their needs at varying points in development and the disease process. For example, the IBD University Web site is targeted to older adolescents transitioning into college who will need to achieve greater independence with their health care.

Children and adolescents with IBD may not look sick, which may lead to difficulties in communicating the intensity of their symptoms and feelings with family members and friends. A support group or discussion forum may provide them with the opportunity to meet and talk with others who are dealing with the same challenges. Many of the sites previously mentioned include support communities or discussion forums. For example, the Crohn's & Colitis Foundation of America Web site (<http://www.ccfa.org>) includes a large support community for patients, family members, and friends.

Three patient support communities that have been on the Web for 10 years or more include HealingWell.com (<http://www.healingwell.com>; CD and UC communities), Crohn's Sanity (<http://www.crohns-sanity.org>), and Crohn's Zone (<http://www.crohnszone.org>). All three communities are free and require registration to join their network. It is important to remind children, adolescents, and parents to check the age limit for participation in these Internet communities. Crohn's Zone is described as a community for all ages, whereas the other two communities ask participants to confirm they are at least 13 years of age. Certain topics discussed in forums or blogs on a Web site may be inappropriate for participants of any age or gender, but especially for young children and minors. From a safety standpoint, it is important to remind children, adolescents, and parents to carefully read the "Terms of Service" and "Privacy Policy" on these sites because large support networks cannot monitor each and every activity of individual members.

MOBILE HEALTH APPS AND IBD

Mobile health applications (apps) provide a way for children and adolescents to increase their knowledge and awareness of how IBD affects their lives, track their symptoms, make better decisions about managing their health, and visually communicate these health changes to their health care provider.

The following four mobile health apps may encourage children and adolescents to actively participate in their health care: (a) Crohn's Diary (<http://www.livingwithcrohnsdisease.com>); (b) Crohn's Wellness Widget (<http://www.crohnsandme.com/wellness-widget>); (c) GI Monitor (<http://www.wellapps.com/products/gimonitor>); and (d) myIBD (<http://www.sickkids.ca/IBDacademy/IBD-Mobile-App>). These apps can be downloaded for free to a smartphone and used by children and adolescents to track symptoms, triggers, and treatments; some apps include tracking and reminder functions for medications or clinic appointments. The visual graphics of the tracking results can be shared with a health care provider during a clinic visit or in some cases sent to them by e-mail during a flare-up to aid in adjusting the treatment plan. More important, committed patients and providers who use these tools may have greater insight and more reliable data on which to base management decisions (Collins, 2012).

Back to the Future

Children and adolescents with IBD face the lifelong challenge of a chronic, often embarrassing disease that is difficult to talk about. New technologies are helping children and adolescents with IBD be more informed about their health, monitor their health, and talk with others who share similar health concerns. How do we integrate these new technologies into clinical practice to help youth keep IBD under control and safeguard their quality of life now and in the future?

Prescribing Web sites is now a patient expectation. Prescribing mobile health applications to deliver more personalized and effective health care? It is now in pilot testing (<http://www.happtique.com/mrx>). Hang on!

New technologies are helping children and adolescents with IBD be more informed about their health, monitor their health, and talk with others who share similar health concerns.

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